2016

Barriers to fistula repair in Uganda: A formative study

Population Council

brief

BARRIERS TO FISTULA REPAIR IN UGANDA: A FORMATIVE STUDY

INTRODUCTION

Obstetric fistula is a preventable and treatable maternal morbidity condition, which occurs in some low-income countries, caused by prolonged obstructed labor that results in a hole between the vagina and the bladder or rectum through which urine or feces leak. Unrepaired fistula can lead to lifelong ostracism, stigma, and shame.

A formative research study was conducted in Uganda, building on upon the results of a systematic review (see side panel) to better understand the barriers and enabling factors for fistula repair care delivery and access. Understanding how Ugandan women living with fistula decide to seek care, identify and reach medical centers, and receive adequate and appropriate care is integral and continues to influence the design of a larger implementation pilot. This study focuses on Fistula Care *Plus* project-supported treatment facilities where fistula camps are routinely held.

METHODOLOGY

Seventy-three in-depth interviews (IDIs) and eight focus group discussions (FGDs) were conducted in Hoima and Masaka, in and around Hoima Regional Referral Hospital and Kitovu Mission Hospital, respectively, from October to December 2015. The data captured a range of perspectives from those with personal or professional fistula experience, for both individual and group narratives of the experiences of those affected by fistula in Uganda.

TABLE 1: SAMPLE BREAKDOWN

	Hoima	Masaka	Total
IDIs	40	33	73
Women affected by fistula	20	15	32
Spouses and other accompanying family members	6	5	11
Providers at camps	10	10	20
Facility and district managers	4	3	7
FGDs	4	4	8
Post-repair clients	2	2	4
Community stakeholders —women	1	1	2
Community stakeholders —men	1	1	2
Total			80

SYSTEMATIC REVIEW

To identify and understand the delays in accessing and receiving treatment and corresponding barriers, document interventions that help to overcome barriers, and to specify gaps in the literature that require further research, we conducted a systematic review of peer-reviewed and grey literature.

Based on the frequency of barrier themes noted in the included articles, nine categories of barriers were identified.

- Psychosocial
- Cultural
- Awareness
- Social
- Financial
- Transportation
- Facility shortages
- Quality of care
- Political

The studies mentioning each of these nine barriers were tallied and the Thaddeus and Maine's (1994) Three Delays Model provided theoretical guidance to classify the barriers to accessing obstetric fistula care.

AUGUST 2016

USAID FROM THE AMERICAN PEOPLE
Fistula Care *Plus*
EngenderHealth
POPULATION COUNCIL

KEY FINDINGS

Prevailing views indicate that barriers and enablers of access to fistula repair care are clustered around awareness, psychosocial, cultural, social, financial, transportation, facility shortages, quality of care, policy and political environment, and healing and reintegration factors (listed below), which influence, in distinct as well as reinforcing ways, the delay to seek care, delay in reaching care, and delay in receiving care once at a hospital. The nuances within each of these categories reveal cross-cutting challenges such as poverty, limited education, gender dynamics, social norms, and political structures affecting fistula prevention and treatment.

CONCLUSION

Evidence supports findings from the systematic review and highlights the importance of women's healing and reintegration into the community. Determinants of care affect each other and access to repair in direct and indirect ways. Related and cross-cutting barriers often involve poverty, early marriage and limited education, gender dynamics within households and communities, and women's agency for making choices about their reproductive health. Though it is difficult to measure the relative influence of each barrier and enabler, awareness, financial, and transport issues consistently emerge as areas to target for policy and programming.

TABLE 2: BARRIERS AND ENABLERS OF FISTULA REPAIR

Domains	Barriers	Enablers
Awareness	*"Some people say the disease is hereditary and it came from their grandmothers..."* —Fistula client, pre-repair	*"When the trainings started, we became aware. [...] the whole village knowing you are the one leaking urine is good, but I emphasize removing fear so that they come to the health facility."* —Community woman
Cultural	*"If a person isn't taught how fistula happens, she will think the co-wife is the one bewitching her..."* —Nurse-counselor	*"What is done here [for camps] is radio announcements that reach very far. When [some]one hears and she knows somebody, a friend or relative, who has this condition, these people also again call. They call those that are very far; where the radios don't reach"* —ANC/Maternity Unit staff
Psychosocial	*"I used to cry all the time, I spent four years crying and bearing in mind that my sister was mistreating me...I refused to eat but I didn't reach an extent of killing or poisoning myself."* —Fistula client, post-repair	*"They should give encouragement and counseling, showing that they aren't the only one with [fistula] in the whole world. They shouldn't [...] stigmatize us like when you pass them they put fingers on their noses."* —Fistula client, post-repair
Social	*"They get disgusted [with] you; your husband gets disgusted, the community members, once they know, get disgusted and say you smell, that you're leaking...Even [family members], it's the same, they gossip."* —Fistula client, living with Fistula	*"Even my maternal relatives know, in fact many people now know about it...they treated me well, they didn't segregate me at all. In fact they took care of me."* —Fistula client, post-repair
Financial/ Transportation	*"You may find a woman at home with no money because as a man, you earn so little so you leave little...some stay very far in villages and so may choose to stay at home."* —Community Man	*"My husband paid for our transport, we had grown beans which we sold and later got money. We first paid off all the debts we had. We used the little balance to come here. After the little [bit] of money was finished, we started borrowing from friends and that's how we are surviving."* —Fistula client, pre-repair
Facility shortages/ Quality of care	*"Health workers around our health centers here are very few. You find them overwhelmed and really tired remember they get very little money as salary so they end up frustrated and replying you any how they wish."* —Community Man	*"That is holistic care, the care that we give them included all the physiological, social, and physical."* —Nurse-counselor
Policy & political environment	*"At the district we have no ambulances. We lack enough qualified staff at the facility. Within the health system, transportation is still lacking, the health workers need training and we also need to sensitize our communities."* —District level manager	*"...they should give us support like they help [people with disabilities] because we are also unable to do work, that is also a disability and so we need support...We also need financial support especially when our husbands do not care about us, we need to survive."* —Fistula client, pre-repair
Healing and Reintegration	*"You can be repaired, but it is not a guarantee that you will be fixed - like me I have been repaired for six times, but up to now it has so far refused."* —Fistula client, pre-repair	*"The counselors after the operation are supposed to link them to community groups that aid them to go back to the community safely."* -Head matron